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Evaluation of Computer-Based Patient Education and an
Interactive Decision Aid

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13. ABSTRACT (Maximum 200 Words) This study aims to examine a method of patient education for men who are seeking treatment for management of localized prostate cancer. The primary goal is to evaluate a recently developed computer-based educational tool (CD-ROM) that is designed to provide treatment-related information and to assist men in making an informed treatment decision. Men are accrued pre-biopsy for a baseline interview, and those who are diagnosed with localized cancer are randomized to receive a CD-ROM with a decision aid, or a CD-ROM with information only. To date, we have accessioned 97 patients. Of the 97, 36 were ineligible and 15 are pending (either pending initial contact or biopsy result). Of the remaining 46, 28 either declined or were unreachable, 2 dropped out and 16 are active with a CD-ROM. This results in a 35% participation rate (16/46). Because of the number of men who are ineligible, and who were unreachable prior to biopsy, we are seeking to expand the study to invite those already diagnosed with prostate cancer to consider participation. To that end, we aim to contact the Georgetown University Radiation Department and Georgetown University Medical Center Referral Center for accrual expansion.				
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Table of Contents

Cover.....	1
SF 298.....	2
Table of Contents.....	3
Introduction.....	4
Body.....	5
Key Research Accomplishments.....	5
Reportable Outcomes.....	5
Conclusions.....	6
References.....	N/A
Appendices.....	6

2/27/03

INTRODUCTION

There is a controversy in the medical community surrounding the utility of treatment options for early stage prostate cancer. Although several options are available for management of localized prostate cancer, no option is clearly superior to others. The primary goal is to evaluate a method of patient education that is designed to provide treatment-related information and to help men clarify their preferences and values via a recently developed computer-based decision aid. We expect that men randomized to the decision aid condition will be more active in their treatment decision and will have improved patient outcomes relative to men assigned to the Information-only condition.

Men will be accrued at the time of their biopsy and those with a positive biopsy result will receive the intervention following notification of the diagnosis but prior to their initial meeting with the urologist in which treatment options are discussed. Participants will be followed at one month and six months post-intervention. The primary outcomes include patient outcomes (knowledge, quality of life, and decisional satisfaction) and shared decision making (SDM) practices.

In many areas of medicine, including treatment of localized prostate cancer, there has been a rapid expansion of research that has resulted in a growing number of diagnostic and treatment options that are available to physicians and patients. In many cases, there are several effective and viable treatment options, but randomized clinical trials assessing treatment effectiveness have not yet been completed. Although the availability of different options will undoubtedly be beneficial in the long run, at present it creates a difficult decision for individuals and physicians who are faced with the choices for which no best answer is known. The proposed study is designed to assist the patient through this decision, by providing information and helping him consider his values.

2/27/03

BODY

We have listed each of the tasks from our Statement of Work, and the associated accomplishments.

Task 1. Finalize accrual procedures and measures to be included (months 1-2).

This study has accomplished the first task from the approved Statement of Work. We have met with our Division of Urology collaborators, and have confirmed procedures for patient accrual at the time patients are on the biopsy schedule. We have also confirmed the method for patient notification of biopsy results so that we may know when it is time to follow up with the T1 interview, if necessary (i.e., if the patient is notified of his biopsy result indicating early-stage prostate cancer). The four questionnaire assessments (T0 baseline, T1 post notification of biopsy results, T2 one-month post intervention, T3 six-months post intervention) have been finalized (see appendices). Further, we have developed a subject tracking system in an Access database, and have developed data entry in the database for the interviews.

Task 2. Conduct participant accrual (months 3-27).

We received approval to conduct Human Subjects research in September, 2002 and have begun patient accrual at the Division of Urology, Georgetown University. If time permitted, we have mailed out a study flyer to potential participants so that they may have an understanding of the study prior to receiving the accrual telephone call. We have accessioned eligible participants and have been conducting baseline interviews over the telephone. We finalized the medical record abstraction form and have accessed patient information from medical chart review.

Task 3. Conduct follow-up assessments (months 4-33).

For task #3, for those who agreed to the study and were diagnosed with early-stage prostate cancer, we completed the T1 follow-up interview and randomized them to either receive the CD-ROM with a decision aid or a CD-ROM with information only. We have also followed through with sending out disengagement letters to those who become ineligible for the project post-biopsy (e.g., due to a negative result).

Task 4. Preliminary data analyses and baseline manuscript (months 4-33).

For task #4, we aim to conduct preliminary data analyses in the next few months.

Task 5. Final analyses and manuscript preparation (months 34-36).

Final analyses and manuscript preparation will be performed and written, respectively, at a later date once data collection is complete.

KEY RESEARCH ACCOMPLISHMENTS

There are no key research accomplishments to report at this time.

REPORTABLE OUTCOMES

There are no reportable outcomes to report at this time.

2/27/03

CONCLUSIONS

This project seeks to aid men in making a decision about early-stage prostate cancer, through the use of a recently developed CD-ROM. Because thus far we have limited our accrual to access only those men who are coming to Georgetown University for a biopsy appointment, we have had a fairly limited participation rate, due mostly in part to many men becoming ultimately ineligible for participation after their biopsy result. Thus, we aim to expand the study to include men who already have a diagnosis of early-stage prostate cancer and are interested in participation (i.e., viewing the CD-ROM, but have not yet made a decision about treatment). This would allow an even greater 'window of opportunity' for accrual, as we would be able to allow more men to become involved in the study. We thus aim to contact the Georgetown University Radiation Department and Georgetown University Medical Center Referral Center for accrual expansion.

We have also considered expanding the study to additional sites, and will seek the necessary approvals from the Department of Defense before proceeding.

REFERENCES

None

APPENDICES

- A. Study Baseline Questionnaire (T0, Pre-Biopsy).....p. 7
- B. Study Follow-up Questionnaire (T1, Post Results Notification).....p.23
- C. Study One-Month Questionnaire (T2, One month post intervention).....p. 28
- D. Study Six-Month Questionnaire (T3, Six months post intervention).....p. 51

2/27/03

APPENDICES

A. Study Baseline Questionnaire (T0, Pre-Biopsy)

Treatment Decision-Making in Early-Stage Prostate Cancer: Evaluation of Computer-Based Patient Education and an Interactive Decision Aid

Verbal Informed Consent

ID: _____ Date of Accrual _____ Interviewer: _____

Time started: _____ Time Ended: _____ Total Time: _____

Hello, my name is _____, and I am calling from Georgetown University. May I please speak with Mr. _____ (participant's name)?

IF NOT AVAILABLE/BUSY, ASK:

What would be the best time to call back? Date _____ Time _____ a.m./p.m.

I am calling to invite you to participate in a research study here at Georgetown University. I am a member of a research team that is conducting this study in collaboration with your physician in the Department of Urology, and understand that you are scheduled to undergo a prostate biopsy. When you made your biopsy appointment, you may have received a flyer that briefly describes this project. Do you recall receiving the flyer? *[Wait for answer then...]* Do you have a few minutes now so I can tell you about the study and to see if you are interested in participating? *[If yes, proceed to paragraph below; if no, ask when it would be best to call back.]*

As we stated in the flyer, we are inviting men who are scheduled to undergo a prostate biopsy to consider helping us with a research study. The purpose of this research study is to evaluate a computer-based health education program that was designed to help men learn more about early stage prostate cancer and treatment options. Not everyone who has a prostate biopsy will have cancer, and after the biopsy results are in, only those men with a certain stage of cancer will be asked to continue in the study. So, even if you decide you might like to participate at this time, we would contact you after the biopsy, if you are still eligible, to see if you would like to continue.

Do you have any questions at this point? *[If yes, answer factually; if no, proceed to next item.]*

The educational computer program is designed to add to – not substitute for the information the doctor provides. The information is designed to help men make an informed decision about their prostate cancer treatment. In addition to evaluating the computer educational program, we will be evaluating factors that play a role in medical decision making about the treatment of early-stage prostate cancer. These issues are important to assess because at this time, there is still a lack of scientific evidence to help patients and doctors know which treatment option for treating early-stage prostate cancer is the best for which patient. Each type of treatment has its own set of side effects, and patient age and personal preferences are factors that must be considered. Patient education and discussion with the doctor are needed in order for men to make an informed treatment decision.

Men who agree to participate in the research project and are diagnosed with early stage prostate cancer will be asked to participate in a series of three telephone interviews and will receive a computer disk (CD-ROM)

2/27/03

with information about prostate cancer and its potential treatments. The interviews will require approximately 15 minutes each to complete, and reviewing the CD-ROM will require between 30 minutes and 4 hours, depending on the amount of time the individual wishes to devote to it. Men who want to participate but do not have access to a computer will be loaned a laptop computer to take home and use for several days. Men who do not feel comfortable using a computer will be provided assistance by the project staff. We also ask men who agree to participate to give us permission to access their medical records for information about their treatment during the course of the research.

In summary, if you agree to participate and your biopsy shows that you are diagnosed with early-stage prostate cancer, then you will be asked to continue in the study and to complete up to 4 telephone interviews over the course of 6 months, to review a computer based educational tool, and to allow us access to your medical treatment records. The total time required for participating in the project ranges from about 15 minutes if you only participate in the first telephone interview up to about 5 hours over the course of the next six months, which includes the telephone interviews and reviewing the educational information. There is no cost for participating. In appreciation for your time, you will receive \$20 if you only need to complete the initial interview, or \$40 if you are eligible to complete the entire project.

Do you have any questions at this point?

Now I would like to tell you about the possible benefits and possible risks of participation. We do not guarantee that men who participate will receive a direct benefit. However, they may benefit from this study by learning more about the different treatments for prostate cancer before making their treatment decisions. Men who participate in this study will be assisting the medical community and other patients with prostate cancer in learning how men make treatment decisions.

The risks of participating in this research study are minimal. Some patients may find the interview or the factual information in the computer program distressing. We encourage everyone to talk with their urologist about their treatment options and if they feel upset after reviewing the information, to discuss their concerns with their urologist. Men who are feeling anxious or depressed about their condition, can let me know or can contact us and we can provide information about prostate cancer support groups or individual counselors or therapists.

Another possible risk involved in this study is potential embarrassment over discussing personal health concerns. We will make every effort to minimize this possibility. Men who agree to participate have the right to refuse to answer specific questions that they feel are too personal or that they simply do not wish to answer, but can still participate in the study if they so choose. Although there is a risk of breach of confidentiality inherent in any research study, the information we obtain will not have the participant's name on it. It will have a code number so the interviewer will be the only person who knows who said what. Only the grouped data will be reported in any presentations or published papers. We will make every effort to minimize such risks so that a participant's comfort and privacy may be ensured. However, official representatives of the Georgetown University Institutional Review Board for the Protection of Human Subjects or the U. S. Army Medical Research and Materiel Command may access the data as part of their responsibility to protect people who participate in research. If they do review the records, they are bound to the same confidentiality requirements that the researchers are.

For men who decide they do not want to participate or who are not eligible to participate, the alternative will be to gather information about treatment options from their urologist and from other sources, such as brochures and pamphlets, the library, and the Internet.

2/27/03

The decision to participate in this study is yours. You have the right to refuse to participate or to leave the study at any time and doing so will not harm your relationship with your physicians or with Georgetown University.

If you have any questions about the study you can contact the principal investigator, Dr. Kathryn Taylor at 202-687-0649. Or if you have any questions about your rights as a research subject, you can contact Elisabeth Crigler at the Georgetown University IRB, 202-687-1506.

Do you have any questions about the project?

Does this sound like something in which you would be interested in participating? ____yes ____no

IF NO: May I ask why you are not interested in participating?

____too busy ____ not interested in topic ____questions too personal ____other:

Do you feel like you need additional time or more information to consider participating? ____yes ____no

IF YES: Would you like me to call you back tomorrow after you have had a chance to think about it? What else would be helpful to you in making your decision?

IF PARTICIPANT IS INTERESTED IN PARTICIPATING:

Has the study been explained to your satisfaction?

IF YES: Do you agree to participate in the initial telephone interview?

The first interview needs to be conducted prior to your upcoming biopsy appointment. This interview will take 15 minutes and will ask questions regarding your background, genitourinary health, prostate cancer knowledge, decisional preferences, and quality of life. You may skip or not answer any specific questions that you do not wish to answer. If your biopsy indicates you are not eligible to participate further, then the information you share may be used in a report concerning men who undergo a biopsy but do not have a diagnosis of early stage prostate cancer. As described above, only the grouped data will be reported in any presentations or published papers and the data will have a code number and not individuals' names. If your biopsy indicates that you are eligible, we will contact you and, if you are still interested, we will make arrangements to get the computer educational program to you. Would it be possible for us to do that interview now?

* * * * *

Okay, do you mind if we go ahead and get started?

(If now is not a good time, when is a good time to call back? _____)

BACKGROUND

I would like to ask you some questions about your background.

1. What is your date of birth? _____month _____day _____year

2. What is your marital status? [DON'T READ LIST]

_____never married

_____married

_____living in a marriage-like relationship

_____separated

_____divorced

_____widowed

_____other: _____

3. Do you have a regular doctor? _____yes _____no

4. Do you have health insurance? _____yes _____no

IF YES: Is the insurance:

_____Private (i.e., paid for by employer, family member's employer, or oneself;
e.g., commercial (bc/bs), HMO, Military/champus, PPO)

_____Public (e.g., Medicaid, medicare)

_____Combination of public and private (e.g., medicare plus 'gap' insurance that
was purchased)

_____Other: _____

5. Do you have access to a computer? _____yes _____no

[IF NO] Do you have access to one in a friend or relative's house or at work? __ yes__no

[IF YES] Do you know when the computer was purchased?

Does it have the capability of running a CD-ROM?

6. How many years of school have you completed? [DON'T READ LIST]

_____8th grade or less

_____some high school

_____high school graduate or GED

_____some college

_____college graduate

_____graduate work/degree

7. Are you currently employed? [DON'T READ LIST]

_____Not employed _____Retired _____Full-time employed _____Part-time employed

2/27/03

8. To which ethnic group do you belong? [DON'T READ LIST]

- ☐ white
☐ black or African American
☐ Hispanic or Latino
☐ Caribbean or West Indian
☐ Asian
☐ Native Hawaiian or Other Pacific Islander
☐ Native American or Alaska Native
☐ Other: _____

PROSTATE CANCER SCREENING HISTORY

1. Do you know the approximate date of your most recent examination for prostate cancer?
____/____/____
2. Was this examination performed by: ☐ your physician
☐ a new physician who you did not know previously
☐ in a free prostate cancer screening program
3. Was the prostate exam done because you were experiencing any prostate-related symptoms (e.g., urinary control, pain)? ☐ yes ☐ no ☐ don't know
4. Do you know the PSA value? _____
5. Was your DRE abnormal? ☐ yes ☐ no
6. Before this last exam, have you ever had an abnormal exam in the past (meaning that your doctor thought there was something that needed to be checked out further)? ☐ yes ☐ no ☐ DK
7. [IF YES] Have you had a prostate biopsy previously? ☐ yes ☐ no ☐ DK
- [IF YES] What the result of the biopsy? ☐ normal, no evidence of cancer
☐ abnormal, diagnosis of prostate cancer [Early close]
☐ abnormal, other: _____
8. How often do you get screened for prostate cancer? ☐ every 3-6 months
☐ annually
☐ every 2 years
☐ less often
☐ don't know
9. Approximately how often would you say you have been screened for prostate cancer in your lifetime?
(This would include the PSA and/or DRE) _____
10. Have you ever been screened in a free, mass screening program? ☐ yes ☐ no

Early Close

Because our study is specifically for patients who have not had a prior diagnosis of prostate cancer, we will no longer require your participation. Thank you for your time and willingness to answer these questions. Please do not hesitate to call us if we can be of any assistance to you at 202-687-0435.

2/27/03

PERSONAL HISTORY OF CANCER

Earlier I asked you about whether you had ever been diagnosed with prostate cancer. Now I would like to ask whether you have ever been diagnosed with any other type of cancer.

_____yes _____no _____not sure

If YES: What type:

Year diagnosed:

OTHER ILLNESSES

Have you been diagnosed with any other major illnesses (e.g., any form of heart disease, diabetes, asthma, etc.) _____yes _____no [IF YES] _____

FAMILY HISTORY OF PROSTATE CANCER

Now I would like to ask a few questions about your family history of prostate cancer.

Have any of your blood relatives ever been diagnosed with prostate cancer?

This would include your father, brother, and sons. _____yes _____no _____DK

IF NO: Go to next section.

IF YES: Verify that he is a blood relative.

Who? _____(father, brother, son)

How old was he when he was diagnosed? _____

Who? _____(father, brother, son)

How old was he when he was diagnosed? _____

Who? _____(father, brother, son)

How old was he when he was diagnosed? _____

UCLA Prostate Cancer Index

The following questions are about your urinary, bowel, and sexual function. These questions may or may not apply to you at this time; however, we would like to ask them just to double-check on your current function.

Urinary Function

This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

1. Over the past 4 weeks, how often have you leaked urine?

Every day.....	1
About once a week.....	2 (Circle one number)
Less than once a week.....	3
Not at all.....	4

2. Which of the following describes your urinary control during the last 4 weeks?

No control whatsoever.....	1
Frequent dribbling.....	2 (Circle one number)
Occasional dribbling.....	3
Total control.....	4

3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks?

3 or more pads per day.....	1
1-2 pads per day.....	2 (Circle one number)
No pads.....	3

4. How big a problem, if any, has each of the following been for you?
(Circle one number on each line)

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
5. Dripping urine or wetting your pants	1	2	3	4	5
6. Urine leakage interfering with your sexual activity	1	2	3	4	5

7. Overall, how big a problem has your urinary function been for you during the last 4 weeks?

No problem.....	1
Very small problem.....	2
Small problem.....	3 (Circle one number)
Moderate problem.....	4
Big problem.....	5

2/27/03

Bowel Habits

The next section is about your bowel habits and abdominal pain. Please consider ONLY THE LAST 4 WEEKS.

8. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks?

More than once a day.....1
About once a day.....2 (Circle one number)
More than once a week.....3
About once a week.....4
Rarely or never.....5

9. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks?

Never.....1
Rarely.....2 (Circle one number)
About half the time.....3
Usually.....4
Always.....5

10. How much distress have your bowel movements caused you during the last 4 weeks?

Severe distress.....1
Moderate distress.....2 (Circle one number)
Little distress.....3
No distress.....4

11. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?

Several times a day.....1
About once a day.....2
Several times a week.....3 (Circle one number)
About once a week.....4
About once this month.....5
Rarely or never.....6

12. Overall, how big a problem have your bowel habits been for you during the last 4 weeks?

Big problem.....1
Moderate problem.....2 (Circle one number)
Small problem.....3
Very small problem.....4
No problem.....5

2/27/03

Sexual Function

The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about the LAST 4 WEEKS ONLY.

How would you rate each of the following during the last 4 weeks?
(Circle one number on each line)

	Very Poor	Poor	Fair	Good	Very Good
13. Your level of sexual desire.....	1	2	3	4	5
14. Your ability to have an erection...	1	2	3	4	5
15. Your ability to reach an orgasm ...	1	2	3	4	5

16. How would you describe the usual QUALITY of your erection?

- None at all.....1
Not firm enough for any sexual activity.....2 (Circle one number)
Firm enough for masturbation and foreplay only.....3
Firm enough for intercourse.....4

17. How would you describe the FREQUENCY of your erections?

- I NEVER had an erection when I wanted one.....1
I had an erection LESS THAN HALF the time I wanted one.....2
I had an erection ABOUT HALF the time I wanted one.....3 (Circle one number)
I had an erection MORE THAN HALF the time I wanted one...4
I had an erection WHENEVER I wanted one.....5

18. How often have you awakened in the morning or night with an erection?

- Never.....1
Seldom (less than 25% of the time).....2
Not often (less than half the time).....3 (Circle one number)
Often (more than half the time).....4
Very often (more than 75% of the time).....5

19. During the last 4 weeks did you have vaginal or anal intercourse?

- No.....1
Yes, Once.....2 (Circle one number)
Yes, More than Once.....3

2/27/03

20. Overall, how would you rate your ability to function sexually during the last 4 weeks?

- Very poor.....1
- Poor.....2
- Fair.....3 (Circle one number)
- Good.....4
- Very Good.....5

21. Overall, how big a problem has your sexual function been for you during the last 4 weeks?

- No problem.....1
- Very small problem.....2
- Small problem.....3 (Circle one number)
- Moderate problem.....4
- Big problem.....5

Knowledge of Prostate Cancer

Please rate each statement as True (T) or False (F) or Don't Know (DK).

I. Statistics Associated with Prostate Cancer

- ☐ 1. Usually, prostate cancer grows very quickly compared to other types of cancer.
- ☐ 2. Prostate cancer is the most common cause of cancer death in men in the U.S.

II. Medical Tests and Tools

- ☐ 3. A man's PSA blood test can be normal even if he has prostate cancer.
- ☐ 4. An abnormal PSA blood test (or high PSA level) does not necessarily mean that prostate cancer is present.
- ☐ 5. A prostate biopsy is used to confirm the diagnosis of cancer.
- ☐ 6. After a man receives treatment for PCa, the PSA level is the main indication that cancer is active again.

III. Watchful Waiting

- ☐ 7. Some experts may suggest that some men with early-stage PCa not receive any treatment for it.
- ☐ 8. In general, doctors believe that older men are more likely to benefit from treatment from prostate cancer compared to younger men.
- ☐ 9. Most men with early-stage prostate cancer who choose to not get treatment will usually die from their disease.
- ☐ 10. For men who select watchful waiting, it is advised to see your doctor every 3-6 months for monitoring of PSA and DRE.
- ☐ 11. All experts agree that compared to watchful waiting, treating early-stage prostate cancer will extend a man's life.

IV. Surgery

- ☐ 12. Surgery is the only method to obtain accurate staging of PCa.
- ☐ 13. Activities may be restricted for up to 4-6 weeks following surgery.
- ☐ 14. Impotence (trouble getting or maintaining an erection) is a common side effect following surgery for prostate cancer.
- ☐ 15. Incontinence (inability to control the flow of urine) can be a side effect of surgery for PCa.

2/27/03

- ___ 16. Surgery to remove the prostate always results in complete loss of fertility (i.e., the ability to have children).

V. External Beam Radiation

- ___ 17. External beam radiation removes the cancerous tumor from the body.
- ___ 18. External beam radiation involves daily outpatient visits for 6-8 weeks.
- ___ 19. Rectal side effects (e.g., inflammation) are likely with external beam radiation.
- ___ 20. There is a 30-50% chance of erectile dysfunction over time after external beam radiation.

VI. Brachytherapy/Seed Implantation

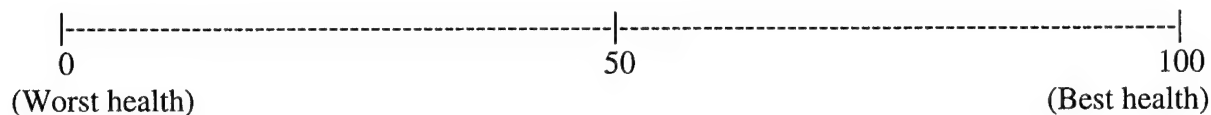
- ___ 21. Men of all ages are eligible for brachytherapy.
- ___ 22. Permanent seed implantation requires a 2-3 day hospital stay.
(*Temporary – 2-3 stay; permanent 1 day outpatient*)
- ___ 23. Loss of fertility is likely after brachytherapy.

Krantz Health Opinion Survey

1.	I usually don't ask the doctor or nurse many questions about what they're doing during a medical exam.	Agree	Disagree
2.	I'd rather have doctors and nurses make the decisions about what's best than for them to give me a whole lot of choices.	Agree	Disagree
3.	Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health.	Agree	Disagree
4.	I usually ask the doctor or nurse lots of questions about the procedures during a medical exam.	Agree	Disagree
5.	It is better to trust the doctor or nurse in charge of a medical procedure than to question what they are doing.	Agree	Disagree
6.	I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately.	Agree	Disagree
7.	I'd rather be given many choices about what's best for my health than to have the doctor make the decisions for me.	Agree	Disagree
8.	Except for serious illness, it's generally better to take care of your own health than to seek professional help.	Agree	Disagree
9.	It is better to rely on the judgements of doctors (who are the experts) than to rely on "common sense" in taking care of your own body.	Agree	Disagree
10.	Clinics and hospitals are good places to go for help since it's best for medical experts to take responsibility for health care.	Agree	Disagree
11.	Learning how to cure some of your own illness without contacting a physician is a good idea.	Agree	Disagree
12.	It's almost always better to seek professional help than to try to treat yourself.	Agree	Disagree
13.	Learning how to cure some of your illness without contacting a physician may create more harm than good.	Agree	Disagree
14.	Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves.	Agree	Disagree
15.	If it costs the same, I'd rather have a doctor or nurse give me treatments than to do the same treatments myself.	Agree	Disagree
16.	It is better to rely less on physicians and more on your own common sense when it comes to caring for your body.	Agree	Disagree

Euroqol question

Now I would like for you to think about how good or bad your health is, on a 100 point scale. Zero is the equivalent of the worst health you can imagine, all the up to 100, which is the best health you can imagine. Where would you put yourself on this scale, in terms of your own current health?



Participant's rating: _____

Cancer Worry

Overall, how worried are you about the diagnosis and treatment of prostate cancer?

- ___ not at all worried
- ___ a little worried
- ___ somewhat worried
- ___ extremely worried

3

SF-12

This next set of questions asks for your views about your health.

1. In general, would you say your health is: ___Excellent ___Very good ___Good ___Fair ___Poor
 (1) (2) (3) (4) (5)

The following items are about activities you might do during a typical day.

- | | Yes, Limited
A Lot | Yes, Limited
A Little | No, Not
Limited | | |
|---|-----------------------|--------------------------|--------------------|--------------------|------------------|
| 2. Does your health now limit you in terms of moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1 | 2 | 3 | | |
| 3. Does your health limit you in terms of climbing several flights of stairs | 1 | 2 | 3 | | |
| 4. During the past 4 weeks, have any problems with your physical health resulted in your accomplishing less than you would like | Yes (1) | No (0) | | | |
| 5. During the past 4 weeks, have any problems with your physical health limited you in the kind of work or other activities that you do | Yes (1) | No (0) | | | |
| 6. During the past 4 weeks, have any emotional problems such as depression or anxiety resulted in your accomplishing less than you would like | Yes (1) | No (0) | | | |
| 7. During the past 4 weeks, have any emotional problems resulted in your not being able to do your work or other activities as carefully as usual | Yes (1) | No (0) | | | |
| 8. During the past 4 weeks, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)? | Not at all
(0) | A little bit
(1) | Moderately
(2) | Quite a bit
(3) | Extremely
(4) |

2/27/03

These next three questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks. . .

	All	Most	A Good Bit	Some	Little	None
*9. Have you felt calm and peaceful?	1	2	3	4	5	6
10. Did you have a lot of energy?	1	2	3	4	5	6
*11. Have you felt downhearted and blue?	1	2	3	4	5	6
*12. Have you felt happy?	1	2	3	4	5	6
*13. Have you felt nervous?	1	2	3	4	5	6
*14. Have you felt down in the dumps?	1	2	3	4	5	6

15. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

___All of the time ___ Most of the time ___Some of the time ___A little of the time ___None of the time

* *Items are from the MHI-5.*

AT INTERVIEW CLOSE:

Thank you very much for your time today. Do you have any questions about the project at this point?

I would just like to spend a couple of minutes telling you what will happen next. In 3-4 days you will receive two copies of the formal consent form, which outlines everything I have told you about the project. As soon as possible after receiving it, please read and sign one copy and return it to us in the enclosed envelope. The other copy will be yours to keep for your records.

Approximately one week following your biopsy, your urologist will call you to tell you the results. If you are no longer eligible to participate in this study, you will receive a letter and \$20 from us thanking you for your participation, and we will not contact you further.

If your biopsy is abnormal and indicates early-stage cancer, then I will call you within a day or two of when you receive your biopsy result to conduct the second interview, and to arrange to send the computer program (CD-ROM) to you for you to use. Does this sound ok?

Thank you again, and I will talk with you soon.

2/27/03

B. Study Follow-up Questionnaire (T1, Post Results Notification)

Treatment Decision-Making in Early-Stage Prostate Cancer:
Evaluation of Computer-Based Patient Education and an Interactive Decision Aid

Verbal Informed Consent—First Follow-up Interview (T1)

ID: _____ Date of T1 _____ Interviewer: _____

Time started: _____ Time Ended: _____ Total Time: _____

Hello, my name is _____, and I am calling from Georgetown University. May I please speak with Mr. _____ (participant's name)?

IF NOT AVAILABLE/BUSY, ASK:

What would be the best time to call back? Date _____ Time _____ a.m./p.m.

As you know, we spoke on the phone a few weeks ago regarding your participation in our study on education and decision making regarding treatment for prostate cancer. I am calling to conduct our first follow-up interview for the study. But first, I would like to verify that you are still interested in participating in this study. ___yes ___no

IF YES: Continue on.

(If now is not a good time, when is a good time to call back? _____)

IF NO: May I ask why you are not interested in continuing to participate?

___too busy ___not interested in topic ___questions too personal ___other:

I understand that you have undergone your biopsy and that Dr. _____ (Regan/Lynch) has called to speak with you about your positive biopsy result. I realize this may be a difficult time for you and your family as you consider various treatment options. As you recall, the purpose of this project is to assess the effectiveness of an educational tool to help patients during this time. You will be receiving a copy of the computer disk within the next couple of days. In addition, we need to conduct our second interview at this time. The interview should take us about 20 minutes to complete. Is this a convenient time?

IF YES: Begin with T1 interview.

(If now is not a good time, when is a good time to call back? _____)

Do you have any questions about the study at this time?

2/27/03

DECISIONAL CONFLICT SCALE—Short Form

I would like for you to think about your decision about treatment for prostate cancer.

I will read a list of statements about your decision. These things may or may not apply to you. You can answer yes or no to each question.

- | | | | |
|--|----|-----|--------|
| 1. Are you clear about which choice is best for you? | No | Yes | Unsure |
| 2. Do you feel sure about your decision? | No | Yes | Unsure |
| 3. Do you know which options are available to you? | No | Yes | Unsure |
| 4. Do you know the advantages of each option? | No | Yes | Unsure |
| 5. Do you know the disadvantages of each option? | No | Yes | Unsure |
| 6. Are you clear about which of the advantages are most important to you? | No | Yes | Unsure |
| 7. Are you clear about which of the disadvantages are most important to you? | No | Yes | Unsure |
| 8. Do you have enough support from others in order to make a decision? | No | Yes | Unsure |
| 9. Are you making a decision without any pressure from others? | No | Yes | Unsure |
| 10. Do you have enough advice to make a decision? | No | Yes | Unsure |

**Wallston Desire for Control over Health Care
(DCON)**

Please indicate the extent to which you agree or disagree with the following statements. Think of these in terms of **what you want as a patient in your treatment for prostate cancer.**

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I want to have a say in what will be done to me.				
2. I want the doctors and nurses to decide what is best for me.				
3. I want to know in advance which procedures will be used.				
4. I want to influence the kind of care that I get.				
5. I do not want to know in advance what the procedures will feel like.				
6. I want to know what the procedures will do to me.				
7. I want to have a say in what procedures I get.				

Degner Control Preference Scale

Overall, how do you think you will prefer your prostate cancer treatment decisions be made?

- ___ I prefer to leave all decisions regarding treatment to my doctor.
- ___ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- ___ I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
- ___ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.
- ___ I prefer to make the decision about which treatment I will receive.

Treatment Choice Predisposition

Common choices that men have with regard to treating prostate cancer include the following:

- 1) Surgery to remove the prostate
- 2) Radiation therapy to destroy the prostate cancer cells
- 3) Radioactive seed implants to destroy the prostate cancer cells
- 4) Watchful waiting, or treating the cancer if there are signs that the cancer is progressing

At the moment, are you leaning towards any specific treatment for your prostate cancer?

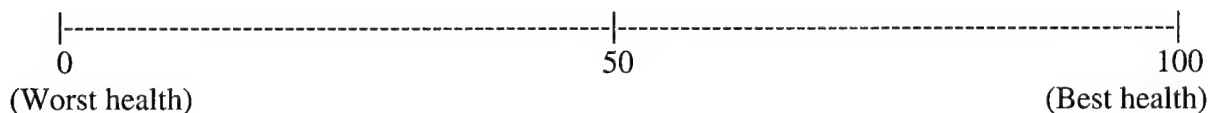
If so, what treatment? _____

If you do not decide on that treatment, what would you choose? _____

Further, if you do not decide on this (previous) treatment, what then would you choose?

Euroqol question

Now I would like for you to think about how good or bad your health is, on a 100 point scale. Zero is the equivalent of the worst health you can imagine, all the up to 100, which is the best health you can imagine. Where would you put yourself on this scale, in terms of your own current health?



Participant's rating: _____

Cancer Worry

Overall, how worried are you about the diagnosis and treatment of prostate cancer?

- ___ not at all worried
- ___ a little worried
- ___ somewhat worried
- ___ extremely worried

2/27/03

Mental Health Index 5
(MHI-5)

These next five questions are about how you feel and how things have been for you during the past 4 weeks. For each question, please give one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All	Most	Good bit	Some	Little	None
1. Have you felt calm and peaceful?	1	2	3	4	5	6
2. Have you felt downhearted and blue?	1	2	3	4	5	6
3. Have you felt happy?	1	2	3	4	5	6
4. Have you felt nervous?	1	2	3	4	5	6
5. Have you felt down in the dumps?	1	2	3	4	5	6

AT INTERVIEW CLOSE:

Thank you very much for your time today. Do you have any questions about the project at this point?

I would just like to spend a couple of minutes telling you what will happen next. I am going to send the program (CD-ROM) to you for you to use before your subsequent meeting with Dr. _____ (Regan/Lynch). From our first interview, you told me that you do/don't have a computer at home or work that you may use. Is this still correct? Also, I want to verify that the computer you have was purchased in 1998 or more recently and that you have a CD-ROM drive, as this will be necessary in order to have the disk work properly. I will also send you a money order in the amount of \$20.

IF Participant needs a computer: I will arrange to send a laptop computer for you to use with instructions about how to set it up. *(Interviewer will work out the details of the best time and location to have a courier deliver the computer to him, and the length of time to keep the computer).*

In one month or so, I will contact you again for the third assessment. We will go over similar questions at that time. Six months from now, we will conduct the fourth/final interview for this project.

Thank you again, and I will talk with you in about a month.

2/27/03

C. Study One-Month Questionnaire (T2, One month post intervention)

Treatment Decision-Making in Early-Stage Prostate Cancer:
Evaluation of Computer-Based Patient Education and an Interactive Decision Aid

Verbal Informed Consent—Second Follow-up Interview (T2)

ID: _____ Date of T2 _____ Interviewer: _____

Time started: _____ Time Ended: _____ Total Time: _____

Hello, my name is _____, and I am calling from Georgetown University. May I please speak with Mr. _____ (participant's name)?

IF NOT AVAILABLE/BUSY, ASK:

What would be the best time to call back? Date _____ Time _____ a.m./p.m.

I am calling to conduct our second follow-up interview for the prostate research study. I want to first verify that you are still interested in participating in this study. ____yes ____no

IF YES: Continue on.

(If now is not a good time, when is a good time to call back? _____)

IF NO: May I ask why you are not interested in continuing to participate?

____too busy ____not interested in topic ____questions too personal ____other:

It has been about one month or so since you received the CD-ROM for this study. I hope you had the time to use the CD-ROM. We are also interested in your evaluation of the CD-ROM. This interview should take us about 30 minutes to complete. Is this a convenient time?

IF YES: Begin with T2 interview.

(If now is not a good time, when is a good time to call back? _____)

Do you have any questions about the study at this time?

UCLA Prostate Cancer Index

The following questions are about your urinary, bowel, and sexual function. These questions may or may not apply to you at this time; however, we would like to ask them just to double-check on your current function.

Urinary Function

This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

1. Over the past 4 weeks, how often have you leaked urine?

Every day.....	1	
About once a week.....	2	(Circle one number)
Less than once a week.....	3	
Not at all.....	4	

2. Which of the following describes your urinary control during the last 4 weeks?

No control whatsoever.....	1	
Frequent dribbling.....	2	(Circle one number)
Occasional dribbling.....	3	
Total control.....	4	

3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks?

3 or more pads per day.....	1	
1-2 pads per day.....	2	(Circle one number)
No pads.....	3	

4. How big a problem, if any, has each of the following been for you?
(Circle one number on each line)

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
5. Dripping urine or wetting your pants	1	2	3	4	5
6. Urine leakage interfering with your sexual activity	1	2	3	4	5

7. Overall, how big a problem has your urinary function been for you during the last 4 weeks?

No problem.....	1	
Very small problem.....	2	
Small problem.....	3	(Circle one number)
Moderate problem.....	4	
Big problem.....	5	

Bowel Habits

The next section is about your bowel habits and abdominal pain. Please consider ONLY THE LAST 4 WEEKS.

8. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks?

More than once a day.....1
 About once a day.....2 (Circle one number)
 More than once a week.....3
 About once a week.....4
 Rarely or never.....5

9. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks?

Never.....1
 Rarely.....2 (Circle one number)
 About half the time.....3
 Usually.....4
 Always.....5

10. How much distress have your bowel movements caused you during the last 4 weeks?

Severe distress.....1
 Moderate distress.....2 (Circle one number)
 Little distress.....3
 No distress.....4

11. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?

Several times a day.....1
 About once a day.....2
 Several times a week.....3 (Circle one number)
 About once a week.....4
 About once this month.....5
 Rarely or never.....6

12. Overall, how big a problem have your bowel habits been for you during the last 4 weeks?

Big problem.....1
 Moderate problem.....2 (Circle one number)
 Small problem.....3
 Very small problem.....4
 No problem.....5

Sexual Function

The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about the LAST 4 WEEKS ONLY.

How would you rate each of the following during the last 4 weeks?

(Circle one number on each line)

	Very Poor	Poor	Fair	Good	Very Good
13. Your level of sexual desire.....	1	2	3	4	5
14. Your ability to have an erection...	1	2	3	4	5
15. Your ability to reach an orgasm ...	1	2	3	4	5

16. How would you describe the usual QUALITY of your erection?

- None at all.....1
 Not firm enough for any sexual activity.....2 (Circle one number)
 Firm enough for masturbation and foreplay only.....3
 Firm enough for intercourse.....4

17. How would you describe the FREQUENCY of your erections?

- I NEVER had an erection when I wanted one.....1
 I had an erection LESS THAN HALF the time I wanted one....2
 I had an erection ABOUT HALF the time I wanted one.....3 (Circle one number)
 I had an erection MORE THAN HALF the time I wanted one...4
 I had an erection WHENEVER I wanted one.....5

18. How often have you awakened in the morning or night with an erection?

- Never.....1
 Seldom (less than 25% of the time).....2
 Not often (less than half the time).....3 (Circle one number)
 Often (more than half the time).....4
 Very often (more than 75% of the time).....5

19. During the last 4 weeks did you have vaginal or anal intercourse?

- No.....1
 Yes, Once.....2 (Circle one number)
 Yes, More than Once.....3

2/27/03

20. Overall, how would you rate your ability to function sexually during the last 4 weeks?

Very poor.....1
Poor.....2
Fair.....3 (Circle one number)
Good.....4
Very Good.....5

21. Overall, how big a problem has your sexual function been for you during the last 4 weeks?

No problem.....1
Very small problem.....2
Small problem.....3 (Circle one number)
Moderate problem.....4
Big problem.....5

Knowledge of Prostate Cancer

Please rate each statement as True (T) or False (F) or Don't Know (DK).

I. Statistics Associated with Prostate Cancer

___ 1. Usually, prostate cancer grows very quickly compared to other types of cancer.

___ 2. Prostate cancer is the most common cause of cancer death in men in the U.S.

II. Medical Tests and Tools

___ 3. A man's PSA blood test can be normal even if he has prostate cancer.

___ 4. An abnormal PSA blood test (or high PSA level) does not necessarily mean that prostate cancer is present.

___ 5. A prostate biopsy is used to confirm the diagnosis of cancer.

___ 6. After a man receives treatment for PCa, the PSA level is the main indication that cancer is active again.

III. Watchful Waiting

___ 7. Some experts may suggest that some men with early-stage PCa not receive any treatment for it.

___ 8. In general, doctors believe that older men are more likely to benefit from treatment from prostate cancer compared to younger men.

___ 9. Most men with early-stage prostate cancer who choose to not get treatment will usually die from their disease.

___ 10. For men who select watchful waiting, it is advised to see your doctor every 3-6 months for monitoring of PSA and DRE.

___ 11. All experts agree that compared to watchful waiting, treating early-stage prostate cancer will extend a man's life.

IV. Surgery

___ 12. Surgery is the only method to obtain accurate staging of PCa.

___ 13. Activities may be restricted for up to 4-6 weeks following surgery.

___ 14. Impotence (trouble getting or maintaining an erection) is a common side effect following surgery for prostate cancer.

___ 15. Incontinence (inability to control the flow of urine) can be a side effect of surgery for PCa.

2/27/03

___ 16. Surgery to remove the prostate always results in complete loss of fertility (i.e., the ability to have children).

V. External Beam Radiation

___ 17. External beam radiation removes the cancerous tumor from the body.

___ 18. External beam radiation involves daily outpatient visits for 6-8 weeks.

___ 19. Rectal side effects (e.g., inflammation) are likely with external beam radiation.

___ 20. There is a 30-50% chance of erectile dysfunction over time after external beam radiation.

VI. Brachytherapy/Seed Implantation

___ 21. Men of all ages are eligible for brachytherapy.

___ 22. Permanent seed implantation requires a 2-3 day hospital stay.
(*Temporary – 2-3 stay; permanent 1 day outpatient*)

___ 23. Loss of fertility is likely after brachytherapy.

**DECISIONAL CONFLICT SCALE—Short Form
(Outcome)**

I would like for you to think about your decision about treatment for prostate cancer.

I will read a list of statements about your decision. These things may or may not apply to you. You can answer yes or no to each question.

1. Were you clear about which choice was best for you?	No	Yes	Unsure
2. Did you feel sure about your decision?	No	Yes	Unsure
3. Did you know which options were available to you?	No	Yes	Unsure
4. Did you know the advantages of each option?	No	Yes	Unsure
5. Did you know the disadvantages of each option?	No	Yes	Unsure
6. Were you clear about which of the advantages were most important to you?	No	Yes	Unsure
7. Were you clear about which of the disadvantages were most important to you?	No	Yes	Unsure
8. Did you have enough support from others in order to make a decision?	No	Yes	Unsure
10. Were you making a decision without any pressure from others?	No	Yes	Unsure
10. Did you have enough advice to make a decision?	No	Yes	Unsure

2/27/03

**Degner Control Preference Scale
(Outcome)**

Overall, how have your prostate cancer treatment decisions been made?

- ☐ My doctor has made all of the treatment decisions.
- ☐ My doctor has made the final decision about which treatment I have had, but s/he has seriously considered my opinion.
- ☐ My doctor and I have shared responsibility for deciding which treatment I will have.
- ☐ I have made the final selection about my treatment after seriously considering my doctor's opinion.
- ☐ I have made the final selection about which treatment I will have.

Information Sources –Part A

In the past 2 weeks, what sources of information have you used to learn about prostate cancer and prostate cancer treatment?

Sources of Information	Please indicate whether you have ever used this source of information	IF YES, how helpful was this information source? 1=very helpful 3=little helpful 2=somewhat helpful 4=not helpful
NCI pamphlets given to you from Georgetown	Yes No	
Other pamphlets or brochures from a cancer organization (NCI, ACS)	Yes No	
Cancer Info Service (800-4-CANCER, NCI)	Yes No	
Telephone info from another cancer organization (e.g, ACS)	Yes No	
Books	Yes No	
Radio shows	Yes No	
Internet	Yes No IF YES: One site of special interest? _____	
Computer-based informational programs (CD-ROM)	Yes No	
Newspaper articles	Yes No	
Videotapes	Yes No	
Television programs	Yes No	
Talking with a family member or friend with PCa	Yes No IF YES: Who? _____	
Talking with a family member or friend without PCa	Yes No IF YES: Who? _____	
Talking with prostate cancer survivors in support group	Yes No	
Talking with your nurse(s)	Yes No	
Talking with your doctor(s)	Yes No	
Other:	Yes No	

Of all of these sources that you used, what were the two most helpful sources of information you used when deciding about your prostate cancer treatment?

A) _____ B) _____

2/27/03

Information Sources –Part B

1. In considering treatment for PCa, how many doctors have you seen, what was their specialty, and what did they recommend?

Doctor/Specialty	Number Seen	Recommendations of doctor #1	Recommendations of doctor #2
Surgeon/Urologist		<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____	<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____
Radiation Oncologist		<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____	<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____
Medical Oncologist		<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____	<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____
Primary Care Physician		<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____	<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____
Alternative Medicine Practitioner		<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____	<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____
Other Provider Specify: _____		<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____	<input type="checkbox"/> surgery <input type="checkbox"/> radiation <input type="checkbox"/> brachytherapy <input type="checkbox"/> ww <input type="checkbox"/> alternative med <input type="checkbox"/> other: _____

Use and Evaluation of Prostate Cancer CD-ROM

Since our last interview, have you had the chance to use the CD-ROM? If you have not used it, please tell me, because we are trying to evaluate whether men used the CD-ROM and found it helpful in learning about prostate cancer and deciding about treatment options.

_____ Yes, I used it _____ No, I did not use it

IF NO: Answer the following questions and then continue on with interview.

1. It is important for us to learn why you did not use the CD-ROM.
Please tell me if any of these reasons apply to you.

_____ you did not have time to use the CD
 _____ you did not feel you needed more information about prostate cancer
 _____ you used some of it and it didn't seem like something you wanted to continue using
 _____ other: _____

2. Can you think of anything that would have made it more likely for you to have used the CD-ROM?
 _____ yes _____ no

IF YES: What? _____

IF YES:

1. In general, can you give me your overall impression of the CD-ROM? _____

2. What did you like most about the CD? _____

3. What did you like least about the CD? _____

4. Did you have any trouble using the CD-ROM?
 (e.g., any problems with it working properly on your computer, or hearing the voiceover, or it
 being too slow to move from screen to screen, or other difficulty)

_____ yes _____ no IF yes, what? _____

5. Did you use the CD-ROM alone or with others? _____ alone _____ with others _____ both

IF WITH OTHERS: Who used it with you?

_____ spouse _____ sibling
 _____ child _____ parent
 _____ friend
 _____ other _____

6. Did you use the CD-ROM one time, or more than one time? _____ once _____ more than once

2/27/03

7. Overall, approximately how much time did you spend using the CD?

☐ 1/2 hour ☐ 2-3 hrs ☐ 6-7 hrs ☐ 12-13 hrs ☐ 18-19 hrs
☐ 1/2-1 hour ☐ 3-4 hrs ☐ 8-9 hrs ☐ 14-15 hrs ☐ 20+ hrs
☐ 1-2 hrs ☐ 4-5 hrs ☐ 10-11 hrs ☐ 16-17 hrs

8. Do you recall using the CD-ROM prior to your initial office visit to discuss treatment options? Y N

9. How recently did you use the CD-ROM?

☐ within the past few days
☐ within the past week
☐ 2-3 weeks ago
☐ 4 wks ago or more

10. Did you discuss your thoughts or concerns about prostate cancer treatment with anyone after using the CD-ROM? ☐ yes ☐ no

IF YES: With whom?

☐ spouse ☐ sibling
☐ child ☐ parent
☐ friend
☐ health professional (who? _____)
☐ other: _____

11. How would you rate the amount of information in the CD?

☐ much less than was needed to make a decision
☐ a little less than was needed
☐ about the right amount of information
☐ a little more information than was needed
☐ a lot more information than was needed

12. How would you rate the length of the CD?

☐ much too long
☐ a little too long
☐ just about right
☐ should have been a little longer
☐ should have been much longer

13. How clear was the information in the CD?

☐ everything was clear
☐ most things were clear
☐ some things were clear
☐ many things were unclear

14. How balanced and fair did you find the CD?

☐ clearly slanted toward one treatment decision ...>
☐ moderately slanted toward one treatment decision ...> Slanted toward which treatment(s)? _____
☐ a little slanted toward one treatment decision ...>
☐ completely balanced

2/27/03

15. How helpful was the CD in helping you make a treatment decision about prostate cancer?

- ☐ very helpful
- ☐ somewhat helpful
- ☐ a little helpful
- ☐ not helpful

16. Did the CD-ROM make you think of new questions to ask your doctor? ☐y ☐n

17. Did the CD-ROM help you explore the differences and similarities between treatments? ☐yes ☐no

- ☐ very much helped explore the differences
- ☐ somewhat helped explore the differences
- ☐ little helped to understand the differences
- ☐ not helpful

18. Did the information that was presented in the CD-ROM address your questions about prostate cancer and treatment of prostate cancer?

- ☐ Yes, it completely addressed my questions
- ☐ Yes, it addressed most of my questions
- ☐ It addressed some of my questions
- ☐ No, it did not adequately address my questions.

19. Did the CD-ROM make you feel nervous or fearful about prostate cancer treatment?

- ☐ Yes, it made me nervous
- ☐ Yes, it made me somewhat nervous
- ☐ It made me a little nervous
- ☐ No, it did not make me nervous

20. Did the CD-ROM make you feel more relaxed about prostate cancer treatment?

- ☐ yes, it made me much more relaxed
- ☐ it made me somewhat relaxed
- ☐ It made me a little more relaxed
- ☐ It did not make me relaxed

21. Did using the CD-ROM impact your feeling of control over your treatment decision?

- ☐ it increased my sense of control a great deal
- ☐ it moderately increased my sense of control
- ☐ it did not affect my sense of control over the treatment decision
- ☐ it moderately decreased my sense of control
- ☐ it decreased my sense of control a great deal

22. To what extent did you use the CD-ROM compared to other sources of information?

- ☐ I used the CD much more than other sources
- ☐ I used the CD somewhat more than other sources
- ☐ I used the CD equally with other sources
- ☐ I used the CD somewhat less than other sources
- ☐ I used the CD much less than other sources

2/27/03

Primary Care Assessment Survey (PCAS)
Select Items

For the following items, think about the doctor who you are working most closely with concerning your treatment for prostate cancer. Who is this doctor/specialty? _____

Please answer the items based on the following scale:

1 = very poor; 2 = poor; 3 = fair; 4 = good; 5 = very good; 6 = excellent.

Thinking about **talking** with this doctor, how would you rate the following:

- | | | | | | | |
|---|---|---|---|---|---|---|
| a. Doctor's advice and help in making | 1 | 2 | 3 | 4 | 5 | 6 |
| decisions about your treatment for PCa | | | | | | |

Thinking about the **personal aspects** of the care you receive from this doctor, how would you rate the following:

- | | | | | | | |
|---|---|---|---|---|---|---|
| a. Doctor's patience with your questions | 1 | 2 | 3 | 4 | 5 | 6 |
| or worries | | | | | | |

Thinking about how much you **trust** this doctor, how would you rate the following:

- | | | | | | | |
|-----------------------------------|---|---|---|---|---|---|
| a. I completely trust my doctor's | 1 | 2 | 3 | 4 | 5 | 6 |
| recommendations about my | | | | | | |
| treatment for PCa. | | | | | | |

Patient Involvement in Care Scale (PICS)

For the following items, think about the doctor whom you are working most closely with concerning your treatment for prostate cancer. Who is this doctor/specialty? _____

		Agree	Disagree
1.	My doctor asked me whether I agree with his/her decisions about my treatment.	1	0
2.	My doctor gave me a complete explanation for my treatment options.	1	0
3.	My doctor asked me what I believe has caused my PCa.	1	0
4.	My doctor encouraged me to talk about personal concerns related to my PCa treatment.	1	0
5.	My doctor encouraged me to give my opinion about my PCa treatment.	1	0
6.	I asked my doctor to explain the treatment or procedure to me in greater detail.	1	0
7.	I asked my doctor for recommendations about my PCa treatment.	1	0
8.	I went into great detail about my medical symptoms.	1	0
9.	I asked my doctor a lot of questions about my PCa treatment.	1	0
10.	I suggested a certain kind of medical treatment to my doctor.	1	0
11.	I insisted on a particular kind of test or treatment for my PCa.	1	0
12.	I expressed doubts about the tests or treatment that my doctor recommended.	1	0
13.	I gave my opinion (agreement or disagreement) about the types of test or treatment that my doctor ordered.	1	0

Treatment Choice Predisposition

Common choices that men have with regard to treating prostate cancer include the following:

- 1) Surgery to remove the prostate
- 2) Radiation therapy to destroy the prostate cancer cells
- 3) Radioactive seed implants to destroy the prostate cancer cells
- 4) Watchful waiting, or treating the cancer if there are signs that the cancer is progressing
- 5) (Hormone therapy)

At the moment, are you leaning towards any specific treatment for your prostate cancer?

If so, what treatment? _____

If you do not decide on that treatment, what would you choose? _____

Further, if you do not decide on this (previous) treatment, what then would you choose?

Values

We have listed some reasons that men give when deciding for or against a particular treatment for prostate cancer. Please tell me how important each reason is to you, using the following scale: not at all important, a little important, somewhat important, and very important.

In making your decision about treatment, how important is/was...	Not at all important	A little important	Somewhat important	Very important
1) the side effect of impotence				
2) the side effect of rectal damage				
3) the side effect of incontinence				
3) the side effect of infertility				
4) reducing your risk of dying from prostate cancer?				
5) the need to feel that you are doing something active to treat the prostate cancer?				
6) having definitive information about the cancer (e.g., the stage, the grade, and other biological information)?				
7) the opinion of others who are close to you, such as a spouse or other close friend or family member (i.e., concerning what they think is the best treatment for you)?				
8) the risks of undergoing major surgery?				
9) the length of the recovery time following the treatment?				
10) concerns about cost of the treatment?				
11) having the cancer removed from your body?				
12) your doctor (doctors') recommendation for a particular treatment?				
13) your other health problems				

2/27/03

14) worry that side effects of incontinence or impotence will change the way you feel about yourself				
15) the concern about the way my partner will react to the treatment or its side effects				
16) your worry that you might regret your treatment decision				
17) your worry about radiation exposure				
What are other factors that you have considered in making a treatment decision?				
18) (text)				
(19) (text)				

Satisfaction with preparation for decision making

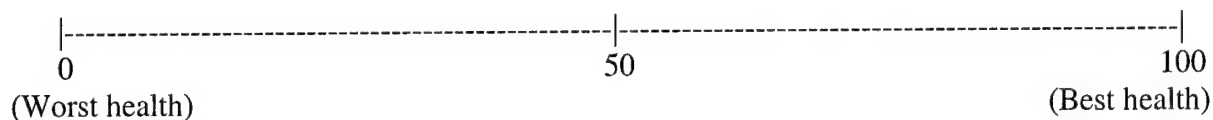
The following questions refer to the computer disk you used to learn about treatments for prostate cancer. Please give your opinion about how well the material prepared you to make a decision about treatment and for doctor visit(s) by indicating how much it helped you. You can indicate that it did not help at all, very little, somewhat, a lot, or that it helped a great deal.

How much did the computer disk....

1. Help you to organize your own thoughts about the decision?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
2. Help you to consider what you think of the pros and cons of each option?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
3. Help you to identify the question you need to ask?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
4. Help you to consider how involved in this decision you want to be?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
5. Help you to know what to expect at the visit with your doctor?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
6. Prepare you to communicate your opinions?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
7. Prepare you to make a better decision?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
8. Make the follow-up visit run more smoothly?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
9. Affect your relationship with your doctor?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal
10. Improve the way time is/was spent during the visit?	1 Not at All	2 Very Little	3 Somewhat	4 A Lot	5 A Great Deal

Euroqol question

Now I would like for you to think about how good or bad your health is, on a 100 point scale. Zero is the equivalent of the worst health you can imagine, all the up to 100, which is the best health you can imagine. Where would you put yourself on this scale, in terms of your own current health?



Participant's rating: _____

Cancer Worry

Overall, how worried are you about the diagnosis and treatment of prostate cancer?

- ___ not at all worried
- ___ a little worried
- ___ somewhat worried
- ___ extremely worried

SF-12

This next set of questions asks for your views about your health.

1. In general, would you say your health is: ___ Excellent ___ Very good ___ Good ___ Fair ___ Poor
 (1) (2) (3) (4) (5)

The following items are about activities you might do during a typical day.

- | | Yes, Limited
A Lot | Yes, Limited
A Little | No, Not
Limited At
All | | |
|---|-----------------------|--------------------------|------------------------------|--------------------|------------------|
| 2. Does your health now limit you in terms of moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1 | 2 | 3 | | |
| 3. Does your health limit you in terms of climbing several flights of stairs | 1 | 2 | 3 | | |
| 4. During the past 4 weeks, have any problems with your physical health resulted in your accomplishing less than you would like | Yes (1) | No (0) | | | |
| 5. During the past 4 weeks, have any problems with your physical health limited you in the kind of work or other activities that you do | Yes (1) | No (0) | | | |
| 6. During the past 4 weeks, have any emotional problems such as depression or anxiety resulted in your accomplishing less than you would like | Yes (1) | No (0) | | | |
| 7. During the past 4 weeks, have any emotional problems resulted in your not being able to do your work or other activities as carefully as usual | Yes (1) | No (0) | | | |
| 8. During the past 4 weeks, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)? | Not at all
(0) | A little bit
(1) | Moderately
(2) | Quite a bit
(3) | Extremely
(4) |

These next three questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks. . .

	All	Most	A Good Bit	Some	Little	None
*9. Have you felt calm and peaceful?	1	2	3	4	5	6
10. Did you have a lot of energy?	1	2	3	4	5	6
*11. Have you felt downhearted and blue?	1	2	3	4	5	6
*12. Have you felt happy?	1	2	3	4	5	6
*13. Have you felt nervous?	1	2	3	4	5	6
*14. Have you felt down in the dumps?	1	2	3	4	5	6

15. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

___All of the time ___Most of the time ___Some of the time ___A little of the time ___None of the time

* *Items are from the MHI-5.*

AT INTERVIEW CLOSE:

Thank you very much for your time today. Do you have any questions about the project at this point?

If you have not already, please follow the directions for the cd-rom file transfer onto the 3.5 inch disk that was sent to you. Then, please return the disk in the stamped disk mailer that was also provided when you received the cd-rom package. Thank you.

I would just like to spend a couple of minutes telling you what will happen next. In six months or so, I will contact you again for the fourth (final) assessment. We will go over similar questions at that time. Thank you again, and I will talk with you in about six months.

2/27/03

D. Study Six-Month Questionnaire (T3, Six months post intervention)

Treatment Decision-Making in Early-Stage Prostate Cancer:
Evaluation of Computer-Based Patient Education and an Interactive Decision Aid

Verbal Informed Consent—Third Follow-up Interview (T3-Final)

ID: _____ Date of T3 _____ Interviewer: _____

Time started: _____ Time Ended: _____ Total Time: _____

Hello, my name is _____, and I am calling from Georgetown University. May I please speak with Mr. _____ (participant's name)?

IF NOT AVAILABLE/BUSY, ASK:

What would be the best time to call back? Date _____ Time _____ a.m./p.m.

I am calling to conduct our third (final) follow-up interview for the prostate research study. I want to first verify that you are still interested in participating in this study. ____yes ____no

IF YES: Continue on.

(If now is not a good time, when is a good time to call back? _____)

IF NO: May I ask why you are not interested in continuing to participate?

____too busy ____not interested in topic ____questions too personal ____other:

It has been about six months or so since you received the CD-ROM for this study. This interview should take us about 30 minutes to complete. Is this a convenient time?

IF YES: Begin with T3 interview.

(If now is not a good time, when is a good time to call back? _____)

Do you have any questions about the study at this time?

UCLA Prostate Cancer Index

The following questions are about your urinary, bowel, and sexual function. These questions may or may not apply to you at this time; however, we would like to ask them just to double-check on your current function.

Urinary Function

This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

1. Over the past 4 weeks, how often have you leaked urine?

Every day.....	1
About once a week.....	2 (Circle one number)
Less than once a week.....	3
Not at all.....	4

2. Which of the following describes your urinary control during the last 4 weeks?

No control whatsoever.....	1
Frequent dribbling.....	2 (Circle one number)
Occasional dribbling.....	3
Total control.....	4

3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks?

3 or more pads per day.....	1
1-2 pads per day.....	2 (Circle one number)
No pads.....	3

4. How big a problem, if any, has each of the following been for you?
(Circle one number on each line)

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
5. Dripping urine or wetting your pants	1	2	3	4	5
6. Urine leakage interfering with your sexual activity	1	2	3	4	5

7. Overall, how big a problem has your urinary function been for you during the last 4 weeks?

No problem.....	1
Very small problem.....	2
Small problem.....	3 (Circle one number)
Moderate problem.....	4
Big problem.....	5

2/27/03

Bowel Habits

The next section is about your bowel habits and abdominal pain. Please consider ONLY THE LAST 4 WEEKS.

8. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks?

More than once a day.....1
About once a day.....2 (Circle one number)
More than once a week.....3
About once a week.....4
Rarely or never.....5

9. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks?

Never.....1
Rarely.....2 (Circle one number)
About half the time.....3
Usually.....4
Always.....5

10. How much distress have your bowel movements caused you during the last 4 weeks?

Severe distress.....1
Moderate distress.....2 (Circle one number)
Little distress.....3
No distress.....4

11. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?

Several times a day.....1
About once a day.....2
Several times a week.....3 (Circle one number)
About once a week.....4
About once this month.....5
Rarely or never.....6

12. Overall, how big a problem have your bowel habits been for you during the last 4 weeks?

Big problem.....1
Moderate problem.....2 (Circle one number)
Small problem.....3
Very small problem.....4
No problem.....5

2/27/03

Sexual Function

The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about the LAST 4 WEEKS ONLY.

How would you rate each of the following during the last 4 weeks?
(Circle one number on each line)

	Very Poor	Poor	Fair	Good	Very Good
13. Your level of sexual desire.....	1	2	3	4	5
14. Your ability to have an erection...1	2	3	4	5	
15. Your ability to reach an orgasm ...1	2	3	4	5	

16. How would you describe the usual QUALITY of your erection?

- None at all.....1
Not firm enough for any sexual activity.....2 (Circle one number)
Firm enough for masturbation and foreplay only.....3
Firm enough for intercourse.....4

17. How would you describe the FREQUENCY of your erections?

- I NEVER had an erection when I wanted one.....1
I had an erection LESS THAN HALF the time I wanted one....2
I had an erection ABOUT HALF the time I wanted one.....3 (Circle one number)
I had an erection MORE THAN HALF the time I wanted one...4
I had an erection WHENEVER I wanted one.....5

18. How often have you awakened in the morning or night with an erection?

- Never.....1
Seldom (less than 25% of the time).....2
Not often (less than half the time).....3 (Circle one number)
Often (more than half the time).....4
Very often (more than 75% of the time).....5

19. During the last 4 weeks did you have vaginal or anal intercourse?

- No.....1
Yes, Once.....2 (Circle one number)
Yes, More than Once.....3

2/27/03

20. Overall, how would you rate your ability to function sexually during the last 4 weeks?

Very poor.....1
Poor.....2
Fair.....3 (Circle one number)
Good.....4
Very Good.....5

21. Overall, how big a problem has your sexual function been for you during the last 4 weeks?

No problem.....1
Very small problem.....2
Small problem.....3 (Circle one number)
Moderate problem.....4
Big problem.....5

Knowledge of Prostate Cancer

Please rate each statement as True (T) or False (F) or Don't Know (DK).

I. Statistics Associated with Prostate Cancer

- ☐ 1. Usually, prostate cancer grows very quickly compared to other types of cancer.
- ☐ 2. Prostate cancer is the most common cause of cancer death in men in the U.S.

II. Medical Tests and Tools

- ☐ 3. A man's PSA blood test can be normal even if he has prostate cancer.
- ☐ 4. An abnormal PSA blood test (or high PSA level) does not necessarily mean that prostate cancer is present.
- ☐ 5. A prostate biopsy is used to confirm the diagnosis of cancer.
- ☐ 6. After a man receives treatment for PCa, the PSA level is the main indication that cancer is active again.

III. Watchful Waiting

- ☐ 7. Some experts may suggest that some men with early-stage PCa not receive any treatment for it.
- ☐ 8. In general, doctors believe that older men are more likely to benefit from treatment for prostate cancer compared to younger men.
- ☐ 9. Most men with early-stage prostate cancer who choose to not get treatment will usually die from their disease.
- ☐ 10. For men who select watchful waiting, it is advised to see your doctor every 3-6 months for monitoring of PSA and DRE.
- ☐ 11. All experts agree that compared to watchful waiting, treating early-stage prostate cancer will extend a man's life.

IV. Surgery

- ☐ 12. Surgery is the only method to obtain accurate staging of PCa.
- ☐ 13. Activities may be restricted for up to 4-6 weeks following surgery.
- ☐ 14. Impotence (trouble getting or maintaining an erection) is a common side effect following surgery for prostate cancer.
- ☐ 15. Incontinence (inability to control the flow of urine) can be a side effect of surgery for

2/27/03

PCa.

- ___ 16. Surgery to remove the prostate always results in complete loss of fertility (i.e., the ability to have children).

V. External Beam Radiation

- ___ 17. External beam radiation removes the cancerous tumor from the body.
- ___ 18. External beam radiation involves daily outpatient visits for 6-8 weeks.
- ___ 19. Rectal side effects (e.g., inflammation) are likely with external beam radiation.
- ___ 20. There is a 30-50% chance of erectile dysfunction over time after external beam radiation.

VI. Brachytherapy/Seed Implantation

- ___ 21. Men of all ages are eligible for brachytherapy.
- ___ 22. Permanent seed implantation requires a 2-3 day hospital stay.
(*Temporary – 2-3 stay; permanent 1 day outpatient*)
- ___ 23. Loss of fertility is likely after brachytherapy.

2/27/03

**DECISIONAL CONFLICT SCALE—Short Form
(Outcome)**

I would like for you to think about your decision about treatment for prostate cancer.

I will read a list of statements about your decision. These things may or may not apply to you. You can answer yes or no to each question.

1. Were you clear about which choice was best for you?	No	Yes	Unsure
2. Did you feel sure about your decision?	No	Yes	Unsure
3. Did you know which options were available to you?	No	Yes	Unsure
4. Did you know the advantages of each option?	No	Yes	Unsure
5. Did you know the disadvantages of each option?	No	Yes	Unsure
6. Were you clear about which of the advantages were most important to you?	No	Yes	Unsure
7. Were you clear about which of the disadvantages were most important to you?	No	Yes	Unsure
8. Did you have enough support from others in order to make a decision?	No	Yes	Unsure
11. Were you making a decision without any pressure from others?	No	Yes	Unsure
10. Did you have enough advice to make a decision?	No	Yes	Unsure

2/27/03

**Wallston Desire for Control over Health Care Outcome
(DCON Outcome)**

Please indicate the extent to which you agree or disagree with the following statements. Think of these in terms of what you felt as a patient in your treatment for prostate cancer.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I had a say in what was done to me.				
2. I let the doctors and nurses decide what was best for me.				
3. I knew in advance which procedures would be used.				
4. I influenced the kind of care that I got.				
5. I did not want to know in advance what the procedures were going to feel like.				
6. I did want to know what the procedures would do to me.				
7. I had a say in what procedures I had.				

**Degner Control Preference Scale
(Outcome)**

Overall, how have your prostate cancer treatment decisions been made?

- ___ My doctor has made all of the treatment decisions.
- ___ My doctor has made the final decision about which treatment I have had, but s/he has seriously considered my opinion.
- ___ My doctor and I have shared responsibility for deciding which treatment I will have.
- ___ I have made the final selection about my treatment after seriously considering my doctor's opinion.
- ___ I have made the final selection about which treatment I will have.

2/27/03

Primary Care Assessment Survey (PCAS)
Select Items

For the following items, think about the doctor who you are working most closely with concerning your treatment for prostate cancer. Who is this doctor/specialty? _____

Please answer the items based on the following scale:

1 = very poor; 2 = poor; 3 = fair; 4 = good; 5 = very good; 6 = excellent.

Thinking about **talking** with this doctor, how would you rate the following:

- | | | | | | | |
|---|---|---|---|---|---|---|
| a. Doctor's advice and help in making | 1 | 2 | 3 | 4 | 5 | 6 |
| decisions about your treatment for PCa | | | | | | |

Thinking about the **personal aspects** of the care you receive from this doctor, how would you rate the following:

- | | | | | | | |
|---|---|---|---|---|---|---|
| a. Doctor's patience with your questions | 1 | 2 | 3 | 4 | 5 | 6 |
| or worries | | | | | | |

Thinking about how much you **trust** this doctor, how would you rate the following:

- | | | | | | | |
|-----------------------------------|---|---|---|---|---|---|
| a. I completely trust my doctor's | 1 | 2 | 3 | 4 | 5 | 6 |
| recommendations about my | | | | | | |
| treatment for PCa. | | | | | | |

Values

We have listed some reasons that men give when deciding for or against a particular treatment for prostate cancer. Please tell me how important each reason is to you, using the following scale: not at all important, a little important, somewhat important, and very important.

In making your decision about treatment, how important is/was...	Not at all important	A little important	Somewhat important	Very important
1) the side effect of impotence				
2) the side effect of rectal damage				
3) the side effect of incontinence				
3) the side effect of infertility				
4) reducing your risk of dying from prostate cancer?				
5) the need to feel that you are doing something active to treat the prostate cancer?				
6) having definitive information about the cancer (e.g., the stage, the grade, and other biological information)?				
7) the opinion of others who are close to you, such as a spouse or other close friend or family member (i.e., concerning what they think is the best treatment for you)?				
8) the risks of undergoing major surgery?				
9) the length of the recovery time following the treatment?				
10) concerns about cost of the treatment?				
11) having the cancer removed from your body?				
12) your doctor (doctors') recommendation for a particular treatment?				
13) your other health problems				

2/27/03

14) worry that side effects of incontinence or impotence will change the way you feel about yourself				
15) the concern about the way my partner will react to the treatment or its side effects				
16) your worry that you might regret your treatment decision				
17) your worry about radiation exposure				
What are other factors that you have considered in making a treatment decision?				
18) (text)				

2/27/03

SATISFACTION WITH DECISION
(Holmes-Rovner Scale)

You have consulted your health care provider about prostate cancer treatment. Answer the following questions about your decision. Please indicate to what extent each statement is true for you AT THIS TIME.

Use the following scale to answer the questions:

1 = Strongly Disagree

2 = Disagree

3 = Neither Agree or Disagree

4 = Agree

5 = Strongly Agree

___ 1. I am satisfied that I am adequately informed about the issues important to my decision.

___ 2. The decision I made was the best decision possible for me personally.

___ 3. I am satisfied that my decision was consistent with my personal values.

___ 4. I expect to successfully carry out (or continue to carry out) the decision I made.

___ 5. I am satisfied that this was my decision to make.

___ 6. I am satisfied with my decision.

2/27/03

Decisional Regret Scale

(Items 1-5 from O'Connor scale; Item 6 from Holmes-Rovner; Items 7-8 from Clark et al., 2001, JCO)

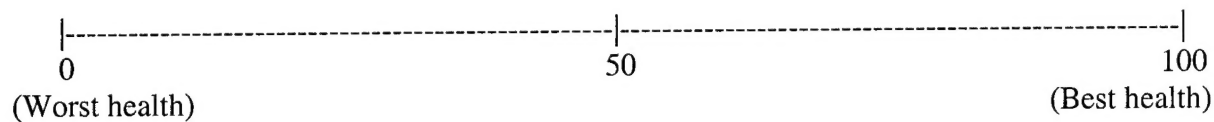
Please reflect on the decision that you made about treatment. Please indicate how strongly you agree or disagree with these statements by using the following 5-point scale:

	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
1. It was the right decision	1	2	3	4	5
2. I regret the choice that was made	1	2	3	4	5
3. I would go for the same choice if I had to do it over again	1	2	3	4	5
4. The choice did me a lot of harm	1	2	3	4	5
5. The decision was a wise one	1	2	3	4	5
6. I am satisfied with my treatment decision	1	2	3	4	5
7. I wish I could change my mind about the kind of treatment I received.	1	2	3	4	5
8. I feel I would have been better off if I had received a different treatment.	1	2	3	4	5

2/27/03

Euroqol question

Now I would like for you to think about how good or bad your health is, on a 100 point scale. Zero is the equivalent of the worst health you can imagine, all the up to 100, which is the best health you can imagine. Where would you put yourself on this scale, in terms of your own current health?



Participant's rating: _____

Cancer Worry

Overall, how worried are you about the diagnosis and treatment of prostate cancer?

- ___ not at all worried
- ___ a little worried
- ___ somewhat worried
- ___ extremely worried

2/27/03

SF-12

This next set of questions asks for your views about your health.

1. In general, would you say your health is:
- | | | | | |
|------------------|------------------|-------------|-------------|-------------|
| (1) | (2) | (3) | (4) | (5) |
| <u>Excellent</u> | <u>Very good</u> | <u>Good</u> | <u>Fair</u> | <u>Poor</u> |

The following items are about activities you might do during a typical day.

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited
2. Does your health now limit you in terms of moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?	1	2	3
3. Does your health limit you in terms of climbing several flights of stairs?	1	2	3
4. During the past 4 weeks, have any problems with your physical health resulted in your accomplishing less than you would like?	Yes (1)	No (0)	
5. During the past 4 weeks, have any problems with your physical health limited you in the kind of work or other activities that you do?	Yes (1)	No (0)	
6. During the past 4 weeks, have any emotional problems such as depression or anxiety resulted in your accomplishing less than you would like?	Yes (1)	No (0)	
7. During the past 4 weeks, have any emotional problems resulted in your not being able to do your work or other activities as carefully as usual?	Yes (1)	No (0)	

2/27/03

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
(1)	(2)	(3)	(4)	(5)

These next three questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks. . .

	All	Most	A Good Bit	Some	Little	None
*9. Have you felt calm and peaceful?	1	2	3	4	5	6
10. Did you have a lot of energy?	1	2	3	4	5	6
*11. Have you felt downhearted and blue?	1	2	3	4	5	6
*12. Have you felt happy?	1	2	3	4	5	6
*13. Have you felt nervous?	1	2	3	4	5	6
*14. Have you felt down in the dumps?	1	2	3	4	5	6

15. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

___All of the time ___Most of the time ___Some of the time ___A little of the time ___None of the time

* Items are from the MHI-5.

AT INTERVIEW CLOSE:

Thank you very much for your time today, and for your participation overall in this study. We very much appreciated your willingness and your time to share your responses on our questionnaires. Please do not hesitate to contact us if you should have any questions about this project in the future. Thank you again.